

**AREA OF SPECIAL INTEREST:**

## Racial and Ethnic Minorities

**SCIENTIFIC ISSUES**

The disproportionate impact of the ongoing HIV/AIDS epidemic upon communities of color has presented significant challenges to biomedical, behavioral, social, and clinical research. The multifaceted nature of the epidemic in general, and specifically within racial and ethnic minority communities, requires a range of research interventions that target those components of the epidemic that facilitate, as well as limit, transmission. Within these communities, the impact of the main routes of HIV transmission in the United States—unprotected sexual intercourse and injecting drug use—are further confounded by other societal and community factors. These factors include poverty, homelessness, immigration, racism, and homophobia. The goal of National Institutes of Health (NIH)-sponsored research in racial and ethnic minority communities is to discover not only the cultural, racial, and social contexts within which HIV transmission is prevented (or is not prevented), but also to determine the impact of interventions at multiple levels within these communities. Finally, NIH seeks, through infrastructural and technical support, to address the paucity of appropriate investigators to address these issues.

**THE IMPACT OF THE  
CULTURAL  
CONTEXT**

Central to the epidemic in racial and ethnic minorities is the influence of social forces, including gender roles and sexual orientation, in risk behavior. These forces are often superimposed upon a context that includes poverty, racism, violence, religion, social stigma, homophobia, the sociocultural roles of women, and the impact of acculturation.

**PRIORITY FOR FUTURE RESEARCH:**

- **Identify the macrostructural forces—including social, economic, and cultural—that create contexts of powerlessness and HIV risk behavior for racial and ethnic minorities.**

Knowledge gained from behavioral interventions in these communities continues to underscore the importance of understanding culture and its impact upon interventions that are not only acceptable, but successful. The rising numbers of minority AIDS cases provide a powerful reminder that behavioral research must continue to define and utilize cultural, social, and contextual factors that affect HIV risk behavior. The role of alcohol and drug use in facilitating HIV transmission through social networks in all communities must also be explored within these social frameworks.

**PRIORITY FOR FUTURE RESEARCH:**

- **Develop, test, evaluate, and disseminate culturally sensitive and appropriate prevention interventions in racial and ethnic minority communities to reduce HIV transmission and acquisition in at-risk social networks. To the maximum extent possible, these interventions should intersect at multiple levels and reflect the role of socioeconomic status and language.**

**UNDERSTANDING  
AND INTERVENING  
IN HIV  
TRANSMISSION**

Through better understanding of social networks and transmission through these networks in minority communities, interventions can be designed, tested, and ultimately tailored to specific population needs. Additional anthropological, behavioral, and social science research is needed to identify those institutions that may serve as entry points into these communities, such as church and community groups. Social marketing research is needed to identify ways to reach more hidden and/or marginalized populations, such as high-risk core transmitters, lesbians of color, gay and bisexual men, drug users, and heterosexual men.

**PRIORITY FOR FUTURE RESEARCH:**

- **Design and conduct research to specifically address vulnerable subgroups within minority communities that are particularly affected by HIV due to a confluence of social, economic, and other factors. Such groups, for whom culturally and contextually appropriate interventions are especially needed, include, but are not limited to, gay men of color, commercial sex workers, the transgendered, women, adolescents, the homeless, the chronically mentally ill, and drug users.**

**HIV TREATMENT  
AND CARE  
RESEARCH FOR  
RACIAL AND  
ETHNIC  
MINORITIES**

Ongoing research on the role of stigma within communities of color is needed not only to identify determinants of high-risk drug and sexual behavior, but also to determine the infrastructure necessary to maintain such research. The impact of community-level homophobia, as well as the impact of disenfranchisement on risk behavior and the impact of drug addiction, are areas that have been identified for additional study. Such factors influence not only the effectiveness of interventions but their durability within social networks as well.

Significant changes in HIV therapy occurred at the end of the past decade, including the advent of protease inhibitor therapy, followed in rapid succession by a growing number of novel and potent therapies. The benefits achieved from these therapies were not uniformly distributed across the diverse communities impacted by HIV infection. Further, the continued and ongoing impact of inadequate drug treatment and the impact of comorbidities—such as sexually transmitted diseases (STDs) and hepatitis C—on racial and ethnic minorities raises a number of clinical research questions.

**PRIORITY FOR FUTURE RESEARCH:**

- **Identify and address gaps in care, treatment, and research manifested by the differentials in access to care and HIV-associated morbidity and mortality in majority and minority HIV-infected communities.**

**INFRASTRUCTURE  
AND SUPPORT**

Minority participation in clinical trials must continue to keep pace with minority representation in the epidemic. For such participation to occur, research to identify the barriers to participation in clinical trials, as well as provider- and client-related barriers and needs, is essential. Identifying underlying community, provider, and individual impediments to clinical trials will help inform the treatment protocols for ethnic and racial minorities.

Research on the impact of the clinical setting upon study enrollment, as well as community acceptance, is of great importance. Incarceration, as well as community perceptions of clinical trials not designed to address their needs, are potential barriers.

**PRIORITY FOR FUTURE RESEARCH:**

- **Identify, define, and address the infrastructural, technical, methodological, and sociocultural needs of communities of color for clinical trial participation.**

Research areas include the impact of community perceptions on individual participation in clinical research, as well as research on novel methodologies for clinical trial recruitment and participation. Trust is the foundation upon which minority participation in clinical, behavioral, and social science research must be built. Despite a legacy of mistrust, racial and ethnic minority participation in clinical research can be, and has been, achieved through a number of creative and diverse mechanisms. These cannot and should not supersede the need for a greater number of racial and ethnic minority scientists to participate in all areas of research.

**PRIORITY FOR FUTURE RESEARCH:**

- **Support and expand programs that train racial and ethnic minority investigators in the areas of behavioral and social science, clinical research, and basic science to increase the number of investigators trained and funded to successfully complete such research.**

## SCIENTIFIC PRIORITIES AND RESEARCH APPROACHES

### PRIORITY FOR FUTURE RESEARCH:

- **Identify the macrostructural forces—including social, economic, and cultural—that create contexts of powerlessness and HIV risk behavior for racial and ethnic minorities.**

### RESEARCH APPROACHES:

- Encourage novel and innovative research designed to explore how social forces affect individuals, groups, and communities and their ability to protect against HIV infection.
- Support innovative and culturally appropriate research designs that explore gender norms in sexual decision making.
- Support intervention research targeting alcohol- and substance-abusing women that is developed within the community and the cultural contexts of the women's lives.
- Support research that explores and evaluates the impact of physical and sexual abuse upon subsequent HIV-risk behavior.
- Encourage and support research that explores, evaluates, and addresses the role of emotional, social, and financial dependence in HIV-risk behavior.
- Support research on culturally focused outreach-based prevention interventions that address risk behavior and misconceptions, especially among adolescent gay men of color.
- Encourage and support research that explores, evaluates, and addresses the impact of perceptions of risk and hierarchy of risk in individual decision making.

**PRIORITY FOR FUTURE RESEARCH:**

- **Develop, test, evaluate, and disseminate culturally sensitive and appropriate prevention interventions in racial and ethnic minority communities to reduce HIV transmission and acquisition in at-risk social networks. To the maximum extent possible, these interventions should intersect at multiple levels and reflect the role of socioeconomic status and language.**

**RESEARCH APPROACHES:**

- Encourage innovative community-level intervention research that addresses unique sociocultural needs, e.g., in gay and bisexual men of color.
- Support studies that examine the normative patterns of sexual behavior among different ethnic or cultural groups.
- Support behavioral intervention research to address psychosocial vulnerabilities among women of color, especially lesbian women.
- Encourage and support innovative research on interventions designed for effecting long-term change in AIDS-related attitudes, beliefs, and behaviors, especially in heterosexual men.
- Encourage and support research on interventions that assess the relative effectiveness of a variety of change agents, including nontraditional community institutions such as the church, the social network, or the community group.
- Support innovative early intervention research for women who seek STD treatment.
- Encourage and support innovative behavior research in heterosexual men, specifically designed to explore gender, cultural, and community influences on adopting and maintaining safe sexual practices.

**PRIORITY FOR FUTURE RESEARCH:**

- **Design and conduct research to specifically address vulnerable subgroups within minority communities that are particularly affected by HIV due to a confluence of social, economic, and other factors. Such groups, for whom culturally and contextually appropriate interventions are especially needed, include, but are not limited to, gay men of color, commercial sex workers, the transgendered, women, adolescents, the homeless, the chronically mentally ill, and drug users.**

**RESEARCH APPROACHES:**

- Support research to develop behavioral interventions for gay and bisexual men of color who combine drugs as well as alcohol with sexual behavior.
- Support research to develop culturally focused outreach-based prevention activities for young ethnic minority transgender individuals.
- Encourage and support innovative research on interventions for homeless and chronically mentally ill persons.
- Encourage and support research to identify and address community perceptions of drug abuse and the role of these perceptions in enhancing or limiting community-based interventions.
- Encourage studies designed to establish the efficacy of culturally specific AIDS prevention strategies in drug treatment and community settings.
- Develop approaches that are culturally sensitive and linguistically appropriate to reach persons in different racial and ethnic minority groups.
- Encourage and support studies that assess and address the impact of comorbid conditions upon treatment readiness, long-term recovery, and adoption of safe behaviors.
- Encourage innovative research that utilizes peer-driven interventions to promote behavioral change among drug and alcohol abusers.

**PRIORITY FOR FUTURE RESEARCH:**

- **Identify and address gaps in care, treatment, and research manifested by the differentials in access to care and in HIV-associated morbidity and mortality in majority and minority HIV-infected communities.**

**RESEARCH  
APPROACHES:**

- Encourage community-based outreach projects that target medically underserved ethnic and minority populations and that provide avenues for ongoing community input.
- Encourage and support research that tests and evaluates the combination of drug treatment and primary health care onsite for alcohol- and drug-abusing populations.
- Encourage and support research that elucidates factors such as alcoholism that result in progression of comorbidities such as hepatitis C, and that modify response to therapy.
- Investigate alternative support structures designed to increase adherence and improved health outcomes, especially for the homeless and the chronically mentally ill.
- Encourage multidisciplinary research to explore, identify, and define the cultural, socioeconomic, racial, and other barriers for providers and patients in the therapeutic relationship.
- Conduct research to develop community-level interventions designed to identify and address the macrostructural forces that undermine or enhance participation in care.



**PRIORITY FOR FUTURE RESEARCH:**

- **Identify, define, and address the infrastructural, technical, methodological, and sociocultural needs of communities of color for clinical trial participation.**

**RESEARCH APPROACHES:**

- Support innovative and culturally sensitive research that focuses upon increased minority participation and retention in clinical trials.
- Encourage ongoing multidisciplinary research that identifies and addresses the cultural, economic, and individual barriers to participation in clinical research.
- Support research to develop novel methodologies that utilize community-based agencies or centers for research information dissemination, recruitment, and participation.
- Encourage and support programs that train research scientists in the sociocultural, anthropological, and economic issues that potentially confound clinical trials for racial and ethnic minority populations.

**PRIORITY FOR FUTURE RESEARCH:**

- **Support and expand programs that train racial and ethnic minority investigators in the areas of behavioral and social science, clinical research, and basic science to increase the number of investigators trained and funded to successfully complete such research.**

**RESEARCH APPROACHES:**

- Develop culturally competent training programs for minority HIV specialists, to include an awareness of cultural issues, as well as responsiveness to specific cultural needs in all aspects of organizational behavior, staff composition and training, and culturally appropriate language in the development of training materials and manuals.
- Develop and expand existing infrastructure within minority communities to disseminate AIDS prevention, treatment, and research information.
- Focus on development of a collaborative relationship between the Historically Black Colleges and Universities (HBCUs), as well as other established centers of higher education for racial and ethnic minorities, for the recruitment of minority investigators and physicians to address minority-specific research and therapeutic considerations.
- Provide widespread dissemination of information on existing opportunities for minorities in biomedical research to ethnic minority communities and organizations and HBCUs, as well as monitor the effectiveness of the techniques used to disseminate such information.
- Strengthen and enhance collaborations with other Department of Health and Human Services agencies to expand existing infrastructures within minority communities to disseminate AIDS treatment and research information efficiently and rapidly to the large numbers of special populations at risk.

**FY 2001 PLANNING GROUP FOR RESEARCH RELATED TO  
RACIAL AND ETHNIC MINORITIES**

**Non-NIH Participants**

**Mr. Moises Agosto, Co-Chair**  
Senior Associate and Director, HIV  
Field Force

**Sallie Marie Perryman, Co-Chair**  
Project Director  
Educational Services  
New York State Department of Health  
AIDS Institute

**Gina Brown, M.D.**  
Associate Professor  
Department of Obstetrics and Gynecology  
Columbia Presbyterian Medical Center

**Rafael M. Diaz, Ph.D.**  
Associate Director  
Center for AIDS Prevention Studies  
AIDS Research Institute  
University of California, San Francisco

**Cyd Lacanienta, M.S.W.**  
Director  
Greater Baltimore HIV Health Service  
Planning Council  
Associated Black Charities of Maryland  
Planning Council Office

**Michael K. Lindsay, M.D., M.P.H.**  
Director  
HIV Prevention in Pregnancy Clinic  
Associate Professor  
Department of Gynecology and Obstetrics  
Emory University School of Medicine  
Grady Memorial Hospital

**Ms. Denise Miles**  
Director of Research Services  
Chicago Prevention Research Project  
Howard Brown Health Center

**George W. Roberts, Ph.D.**  
Special Assistant for Communities of Color  
National Center for HIV, STD, and  
TB Prevention  
Centers for Disease Control and Prevention

**David Vlahov, Ph.D.**  
Director  
Center for Urban Epidemiologic Studies  
New York Academy of Medicine

**Mr. Steven F. Wakefield**  
The Night Ministry  
AIDS Vaccine Advocacy Coalition

**Carmen D. Zorrilla, M.D.**  
Professor  
Department of Obstetrics/Gynecology  
University of Puerto Rico School of Medicine

**NIH Coordinating Committee  
Members**

**Victoria A. Cargill, M.D., M.S.C.E.,  
Co-Chair**  
Director of Minority Research  
Director of Clinical Studies  
Office of AIDS Research, NIH

**Katherine Davenney, M.P.H.**  
Research Epidemiologist  
Center on AIDS and Other Medical  
Consequences of Drug Abuse  
National Institute on Drug Abuse, NIH

**F. Gray Handley, M.S.P.H.**  
Associate Director for Prevention Research  
and International Programs  
National Institute of Child Health and  
Human Development, NIH

**David R. Holtgrave, Ph.D.**

Director

Division of HIV/AIDS Prevention

Intervention Research and Support

National Center for HIV, STD, and

TB Prevention

Centers for Disease Control and Prevention

**Thomas F. Kresina, Ph.D.**

Chief, Biomedical Research Branch

National Institute on Alcohol Abuse and

Alcoholism, NIH

**Wendy Nelson, Ph.D.**

Health Specialist

Division of AIDS

National Institute of Allergy and

Infectious Diseases, NIH